

COMMUNICATING TOGETHER

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AS ABILITIES CHANGE

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Volunteering

SHIRLEY McNAUGHTON



Shirley McNaughton

As someone who is a full-time (independent) volunteer and who interacts with many other full and part-time volunteers, I feel especially qualified to serve as the editor of this issue of **Communicating Together!** In fact, I requested the job (volunteered!) when our associate editors decided that *Community Partnerships and Voluntary Involvement* would be the theme for Winter, 1998 **Communicating Together**. Since all of our associate editors volunteer their contribution to our magazine we are all experts in this issue!

I have always found it difficult over the years to make a clear division between volunteer work and my job — for I have been fortunate during my working life to do what I love. Extending beyond the paid-for time occurred quite naturally as a teacher, administrator, AAC professional during the years 1966-1989. When I “retired”, the “work” continued. Now, however, it is on my own

terms and there is no longer the need to make a distinction between paid and unpaid hours. It is a shared philosophy that makes the days of my husband and myself full of purpose and accomplishment. And it is one of the reasons for a strong bond for us both with Peter Lindsay, who for as long as we have known him, has given equal commitment to “work” and “volunteering”. In fact, Peter and I first met in the early 80’s as we both were volunteering to help establish a computer support program at Bloorview Childrens’ Hospital. (A great fringe benefit of volunteering — the wonderful friends you make!). Since the eighties, we have continued our volunteering and participated extensively in several of the good things in AAC that have resulted from and maintained their service to AAC users thanks to volunteer efforts — ISAAC, BCI and **Communicating Together**. I have always found it easy to understand the position of another friend, Paul Marshall, with regard to job satisfaction. Although Paul says it much more eloquently than I do, we both appreciate how satisfaction can be achieved totally independently of salary. I only wish more people could have the opportunity in life to realize this!

In preparation for writing this editorial, I had planned to re-visit Jeremy Rifkin, whose *End of Work* has offered me a glimpse of hope for a different societal structure in contrast to the growing shift of resources away from society’s most vulnerable and needy persons. Geb Verburg’s *Contexts*, however, in which he considers the thinking of both Rifkin and James Laxer brings

a much broader (and, to me, also more frightening) view of society’s future than I would have been able to contribute. As we consider this issue’s theme of volunteering, Geb Verburg’s *Contexts* juxtapositioned with the other articles, offers many interesting insights.

Many examples of positive experiences made possible through volunteering appear throughout this issue. Our feature article describes a program that combines music with volunteering and sets out the benefits that can be derived. The researching of this article and the linking of “Friends”, music and volunteering, was a labour of love. So was my writing of *Symbol Talk!* I had great empathy in reading the perspectives of Nola Millin, Suzanne Clancy, Steven Smith, Belinda Kligman, Alda Steprans, Steven Hanlon, Audrey McGee, Dorothy Brace, Sherri Maggiacomo, Paul Marshall, Anne Abbott and Bernard O’Keefe. They emphasize the values to be derived from volunteering and community involvement by both the recipient and the volunteer. In talking with Geb and reading his article, however, and in witnessing the decline in volunteering over the past decade, I am reminded of how much volunteer programs are at risk. As you read all the articles in this issue, I hope you will feel motivated to fight for the survival and growth of volunteering. It represents too important a human value to let it disappear. We welcome further comments from our readers as articles or as contributions to our new section to be added next issue — Jim’s *Poet’s Corner*. See pages 5 and 6 for more information.

SHIRLEY McNAUGHTON

It began over thirteen years ago when an event occurred that made the organization, Kitchener-Waterloo (KW) Accessibility (at that time called KW Services for Persons with Physical Disabilities) decide that music should be enjoyed by everyone in their community — and this included the persons this organization served! The director, Chris Hodnett, remembers well how “Music Makers” was conceived. As one of its early recreation programs, KW Services for Persons with Physical Disabilities organized electric wheelchair hockey. After one of the games, the team went to a Karaoke bar to celebrate. Gerrard Fahrenhopf, a team member, surprised everyone by singing a song with a friend that brought the house down. Music ability could indeed reside in persons with disabilities! Inspired by the magic of the evening, the small organization decided music would become one of their programs. They are still involved today in ensuring that a music program is available to their clients, though now their primary role is organizing the transportation with Project Lift in Kitchener-Waterloo.

There were volunteers participating right from the beginning, many

of them music students and others hoping some day to become involved in music therapy. Ann Hall, who directed the music program at Wilfred Laurier University, Waterloo, Ontario, at the time, spread the word about the new program among her students. The response was enthusiastic. “Music Makers” was born. Its members had rhythm, they had their voices, and they were willing to try this new activity. As



Laura Evans & Mike Hinschberger

remembered by Michael Hinschberger, a member of the original group who remains a prominent participant today, “There were eight of us, all strangers. They came and asked us if we would like to try a new music group. We didn’t know what it was about! We were very uptight! It got easier, but it took about a year!”

Music Makers are now Friends

Two years ago, the members of Music Makers decided that some-

thing even more important than music was happening as they met each week, and they changed their name to “Friends”. It was at the end of spring term performance of “Friends” that I first met the group on March 25, 1998. My husband and I, along with two friends, were very moved by both the camaraderie and the musical presentations that we saw. During refreshment time, we talked with the participants and

organizers and sensed the excitement they all felt. We began wondering why this type of musical experience wasn’t available to more persons with physical disabilities. We have since discovered that there are at least three important reasons. For a group like “Friends” to succeed there needs to be a community supportive of music for *all* its members, the skills of music

therapists, and *volunteers*.

“Friends” brings together ten or so persons with all types of physical disabilities, students from the 3rd and 4th years of the Music Therapy Program at Wilfred Laurier University, and volunteers who were students in previous years. This year a high school student is also volunteering. Each year they have two ten-week evening sessions in which they make music together. The group’s activities are co-ordinated by Lynda Tracy, who is a member of the Faculty of Music, Wilfred Laurier

University and who also serves as administrative co-ordinator, Canadian Association of Music Therapy. (See contact information at the end of this article.) The formal link between Music Makers and Wilfred Laurier began in 1986 when Dr. Rosemary Fischer became the director of the newly established Music Therapy Program at the university. Dr. Fischer wanted practicum opportunities for her students and what better way than becoming involved with the Music Makers! There has been no turning back. Each year the group's accomplishments and enjoyment have grown. Highlights from the group's history include being the opening performance at the national conferences of the Canadian Association for Music Therapy in 1990 and 1995, and performing at the Kitchener City Hall during Disabilities Week in 1996.

Music Therapy and More

The benefits of music therapy are many. It provides motivation for achievement and success within an atmosphere that is positive and rewarding to the individual. It offers an avenue for the development of receptive and expressive language and communication skills on both a verbal and non-verbal level. It offers a means of representing emotions through sound. By participating in a wide range of musical activities, there are many opportunities for cognitive growth and increased range of physical movement. During every performance of the group, there is a "special moment" for each member to perform in his or her unique way, with the assistance of their partner. Magic quite frequently occurs! And the learning achieved by

the group members extends to the development of strong social bonds. All of those participating gain special friendships and their understanding of each others' capabilities and needs grows stronger with each year. Lynda Tracy has watched the growth in members as they reach out to help each other with increased confidence. Leadership skills have developed. Sometimes even some friendly competition emerges!

As Lynda shared her insights regarding the benefits of "Friends" with me, I realized she was referring not just to group members with disabilities, but she was referring, as well, to her students and her volunteers. As the music therapy students plan the group goals and individual goals for each person with a disability, they develop knowledge that will enrich their lives long after their training is completed. They gain as much as the members with disabilities in developing an appreciation of the value of every person! Although most of the music students join the group in their first year at university as a music therapy course requirement, many volunteer during their second year and return in subsequent years to help with performances. Last year, a psychology student joined Friends for a one-term credit and returned as a volunteer the second term. As I watched the performance on March 25, I foresaw many future volunteers in the making! Wherever they choose to direct their time, I know they will bring a sensitivity to their role as a result of their experience with Friends. This prediction has since been reinforced by Chris Hodnett. He enthusiastically describes persons who gained their initial volunteer experience

with Friends. They now volunteer in other programs for KW Accessibility.

There is a final performance at the end of each term. The performance of each individual is planned to suit their special capabilities. At the presentation I attended, some accompanied the work of others with the tambourine, maracas, bells or wood block. Some sang, read a poem or told a story to the accompaniment of the piano. There was a musical play with each participant dressed in an exotic costume. Each person had an assistant to provide instruments as needed, to help in positioning, and to sing along when this was desired. Each person had a microphone to ensure that his or her voice or instrumental work carried to the audience. The pride of those in the audience overflowed and could be felt in every corner of the room. The performance was videotaped to be viewed and enjoyed the next term by participants and new students. At their regular weekly sessions, I am told, group members are encouraged to bring examples of their own creativity and the members often improvise music to someone's poem, or act out a story authored by another member. At other times, the group co-authors poems, songs, or stories and interprets them musically and dramatically. They are always eager to try new musical experiences and to explore music technology.

Being a "Friend"

I visited two of the group members to learn their perspectives and find out more about their involvement in Friends. Michael Hirschberger greeted me in his own apartment, a friendly setting with canary hanging in the window and

lots of family photographs. He told me how he along with seven others, all strangers, most with cerebral palsy, came together thirteen years ago to try out this new activity. It took time to develop the group spirit they have today. Michael felt the last five years have been the best because *there has been a volunteer for each member of Friends*. The students are new every year, but, as Michael says, "They are always lots of fun and they always listen to the people they are there to help!" Their roles are varied. They help people who need assistance in order to play an instrument. They help with costumes. They bring food and serve it. They feed those who need help. At the end of each school year there is a party. This is their way of saying thank-you to the volunteers. Michael commented: "Friends couldn't work without volunteers! The group has

gotten better all through the years. Those who are helping have had a lot to do with this!" He especially likes the more sophisticated instruments which are brought to the group by Dr. Roger Knox, who directs the music therapy program at the Bloorview-MacMillan Centre in Toronto and serves as a consultant to Friends. Last year, Dr. Knox brought an electronic keyboard and a sound beam to the sessions. This opened up a wide new universe of musical sounds that could be accessed by the group members!!

Next I visited Jim Stuart who joined the group upon seeing how much it was enjoyed by his friend, Jennie (who later became his wife). Jim gives music therapy credit, first within his rehabilitation program and then in Music Makers, for helping him to gain back his speech and reduce his stuttering. Jim was in-

volved in a serious motor accident in 1984, was in a coma for six months, and then faced life with a prognosis that offered little hope for speech, mobility, hand function or any level of independence. He has worked hard over the years to prove the doctors wrong. Today he lives in his own apartment, operates an electric wheelchair and is an avid computer user. He describes himself as "a big ham!" He stresses how much easier it is to sing than to talk and is a strong vocal advocate for music therapy! Jim has also discovered the joy of writing poetry. He gave me several of his poems as his way of helping me understand his experience in living with a disability and to share his feelings about Friends and volunteers. Two of his poems provide a fitting ending to our look at *Friends, Music and Volunteers*.

(See page 6.)



Jim Stuart & Jenny Scott

Re ComTog OnLine

You will notice that the banner on our cover contains no website address for **ComTog OnLine**. We are having to change our address, and at time of printing the new address has not been confirmed. A notice to all **ComTog OnLine** subscribers is being included as this issue of **Communicating Together** is mailed. For those who wish to browse and explore a sample issue, watch for the banner on the next issue of **Communicating Together**. Our new **ComTog OnLine** address will be there!

POET'S CORNER

Postscript

Jim Stuart shared with me a dream he had of a Disabled Poets' Society (DAPS) — a forum for disabled writers and able-bodied writers to “get together, to exchange ideas and concepts, and possibly create a few collaborative works.” As we talked, the idea emerged of a Poet's Corner in **Communicating Together**, as a venue for **Communicating Together** readers and others with poems to share that are related in some way to each issue's theme. I asked Jim if he would contribute his poems and if he would host this section of **Communicating Together**. He agreed! So, we invite the following writers to contribute to

Jim's *Poet's Corner* (the criteria are taken from Jim's proposed DAPS): poets who “don't just write about being disabled, who write about love, adventure, who can put the fact that they are disabled off to one side.” The theme for the next issue is “Dealing with Change”. If you wish to write a poem on this topic, send it to Jim Stuart, 50 Mooregate, Apt 512, Kitchener, Ontario, Canada, N2M 5G6 by March 15, 1999. Or better still, email your poem to <jstuart@golden.net>. The poem that Jim judges to be best will be printed in the spring issue of **Communicating Together**. Good luck!

To enquire about music therapy in your area, contact:

Canadian Association for Music Therapy,
Wilfrid Laurier University,
Waterloo, Ontario, Canada
N2L 3C5

Phone: 519-884-1970 ext. 6828.

E-mail: ltracy@machl.wlu.ca

Friends

by James Stuart

We are all friends making music together.
We are Donna on guitar
Debbie and Dean on drums
Then Mike gives us something to laugh at.

Sue puts the glamour in the group
Then there's the two love birds
First there is Jenny who loves her man
Then there's James who is good with a pen.

Heather, Karen and Leanne
Help us make our music
Following our faithful leader Lynda
We are all friends making music together.

A Volunteer

by James Stuart

Volunteering's an attitude within you,
A talk you always can continue,
A feeling you have known awhile,
A thought that sparks an inner smile.

A volunteer's a person you hold dear,
Who ventures far, yet stays quite near,
Whose presence sets the spirit free,
Who brings out candor, honesty.

A volunteer shares all your joys and tears,
Feels triumph with you, yet knows your fears,
Accepts your strengths and weaknesses, too,
Won't let small things dull friendship's hold.

A volunteer will walk that extra mile with you,
And cherish values sound and true,
Though paths may sometimes drift apart,
But the true friendship never leaves the heart.

The Need to be Needed

NOLA MILLIN



Nola Millin

I think most people have a desire to feel needed and useful in their society. Many individuals have ways of fulfilling this desire. They have families, jobs, and activities that make them feel like they are accomplishing something, or in many cases, a lot of things. A person's roles can vary but when all is said and done, the roles help make life very rewarding. An individual can be spouse, parent, employee and/or employer, committee member, coach, and countless other roles in a given day or week. Who we are and what we do often gives us a sense of self-worth and a sense of contributing to our community.

One of the various roles a person may have is that of being a volunteer. Volunteering one's time is often very satisfying. I have found that volunteering helps me to feel as though I contribute to my community. Having been unable to find employment until recently, my volunteer experience allowed me to be a "somebody."

Besides giving me something to do, I found that by volunteering I usually have responsibilities and obligations to fulfill. If I'm not heading out to a meeting or to a commitment, I'm at home working on a project that I've volunteered (or have been volunteered!) to do. I know my volunteer experience has been priceless. Even though I have a physical disability, I've always found ways to volunteer and to feel productive.

Most of my volunteer experience has involved sitting on committees. I realize that to have a person with a disability on a committee isn't always easy. Other members have to have a willingness to allow the person to participate. They need to realize that it takes me longer to formulate my responses. A lot of time I prefer them to keep discussing an issue while I type what I want to say into my communication device. When I know there's going to be an item on the agenda that I have strong opinions about, I will prepare my opinion ahead of time and I'll let the chairperson know that I have something to say on that topic. This allows me to participate but it saves time for the other members. In order for me to participate on some of these committees, other minor adjustments have been made. One of these adjustments has been holding some of our meetings in the lounge of the apartment building where I live. Having the meeting where I live saves me the expense and hassle of transportation. If we need to call a meeting suddenly I can still attend. Arranging transportation on the spur of the moment can be very difficult for disabled people. I'm certainly not saying that all of the committees that I sit on meet here but various organizations have found it easier to come to me. As well, during my two year tenure as president of a board, often the executive director

would come here to discuss issues or to get cheques signed. With these courtesies, I have been able to sit on numerous committees and have gained a wealth of experience. I feel very useful and I know I'm contributing something to my community.

Sitting on committees is certainly not the only way a person with a disability can be a volunteer. Although I feel my input to some of these committees is very effective and influential, I have other volunteer positions that give me a tremendous sense of giving something to my community. I have gone to the same church for 18 years. I felt a part of the congregation but it seemed as though there wasn't a volunteer position I could do. Although an individual doesn't need to be a volunteer to be a part of our church, our church is typical in that there are always volunteers need for one thing or another. Obviously, I had a desire to help out in some capacity. A little over a year ago, a volunteer position became available that I could do. The editor of the monthly newsletter was leaving and she needed a replacement. She and I were friends so we discussed what it would take for me to do the job. Part of the problem was that she was also one of the church secretaries so the church staff would give her their handwritten articles and she would just type them into the newsletter. With a few arrangements, I have been able to get a monthly newsletter out. The church staff now e-mails me their articles, which saves me time typing them. My main responsibility is to arrange articles, add clip-art, and make sure everything fits into the format. Once the newsletter is done, I e-mail it to the church where they print it and get it ready for distribution. Because I'm now the newsletter editor, I've gotten to know people in my church whom I didn't know before. It has

given me a real sense of belonging to my community. I'm giving back something to my church, which gives so much to me.

Until a few weeks ago, all of my volunteer experiences have been within my comfort zone. Although my experiences have been a little challenging and frustrating at times, they didn't make me go anywhere where I wasn't familiar. About four weeks ago, I started volunteering at a nursing home. I volunteer through an agency called Citizen Advocacy, which I've been involved with for many years. Citizen Advocacy has established a new program where they train people with disabilities to be Peer Advocates. The thinking is that a person with a disability might be more willing to open up to someone who also has a disability rather than opening up to someone who looks like a "professional." Since I have some physical limitations, I felt a nursing home setting would be a good place to go to see if the residents needed my services. As I said in the editorial of the fall issue, a nursing home is a very foreign place to me. I remember the first day that I went there. I felt bewildered when I entered the facility and the door locked behind me in order to prevent some residents from wandering. A code has to be punched into a keypad to get out. Because I

didn't know anyone and I was unfamiliar to the surroundings I felt trapped. As I'm getting to know the residents, I'm beginning to feel more comfortable. My main role is to provide friendly visits to some of the residents and just make sure they're being well cared for and are getting whatever they need. I find it challenging and a little frustrating at times because the residents tend to forget what I've told them the previous week and other times they fall asleep during a conversation. I'm learning a lot from the residents but I often wonder if I'm providing them with anything. If nothing else happens I know this is one volunteer experience where I'm going to gain a wealth of insight and do some personal growing but hopefully I'll make a few friendships along the way.

Something else that has helped me feel a part of my community is the speaking engagements I do. I do a lot of engagements for free or for the cost of my transportation expenses. I speak to both adults and to children. I go into various grade schools and speak to classes about my disability. One of the groups that I enjoy speaking to is kids at the Children's Rehabilitation Centre. I like being able to encourage these special needs children to be as independent as their life will allow. When I talk to kids, I get the

sense that I'm giving some encouragement to them just like someone gave me the encouragement to keep pursuing my goals.

For a person with a disability, volunteering can be a very vital aspect of our lives. I, personally, don't have any employment experience but a lot of people are impressed with what I've encountered through volunteering. Because of a lot of my volunteer experience, I have gained enough confidence to start my own business. With monies through the Opportunities Funds, I have been able to pursue my dreams. I now have a Motivational Speaking business and I do multi-media editing on the side. When I presented my business plan, the reviewer saw all of my volunteer experience and he was certain I was on the right track with my business ideas. (By the way, the reviewer was impressed that one of my volunteer positions is being an associate editor of an international magazine, too.) Being a volunteer has helped me feel like I'm a productive member of society. I have gained infinite wisdom and have learned how to deal with people in or out of my comfort zone. I hope that same confidence will make me a successful business woman so I can give even more back to my community.

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ISAAC, P.O. 49,
The Donway West, Suite 308,
Toronto, ON, Canada, M3C 3M9**

Volunteering over the Lifespan

SUZANNE CLANCY



Suzanne Clancy

As I ponder what to write about volunteers, I am drawn back to my youth and my own volunteer efforts as a young stay-at-home mom. Being blessed with much energy, a supportive husband, and having limited resources, I was anxious to make a contribution to my local community. Perhaps this came from my rural background, where neighbour helped neighbour, in good times and bad.

My first foray into volunteerism was as a Girl Guide leader. I next oversaw a Saturday morning cooking class for a group of inner city youth. I soon realized that this group had more problems than I was trained to deal with and gladly handed the program over to more qualified individuals. Undaunted, I registered with the local volunteer bureau and accepted the challenge of dressing 25 dolls for the Christmas Gift Basket Drive. This was a task I thoroughly enjoyed and even our young sons had great fun watching mommy dress her *babies*.

My volunteer days came to an abrupt end when I returned to work full-time while my husband went back to university. Family, work, and my own part-time studies were more than enough to keep me occupied and to sap my energy. It would be another 10 years before I would venture again into the world of the volunteer, and this time I would be not the volunteer, but the beneficiary.

For 20 years now, my work as a teacher of special needs adults has been greatly enhanced through the aid of many dedicated volunteers. While my work is held in high regard, I certainly would not have been able to achieve nearly as much were it not for my many volunteers.

Early in my career as a literacy instructor, my two teenage sons were volunteer literacy and numeracy tutors, coming to class two evenings a week and working one-on-one with the students. Their help enabled me to enlarge my class and offer the program to greater numbers of recently deinstitutionalized individuals who were struggling with the demands of community living.

As I developed additional programming, and my sons grew up and moved on to other things, I came to rely on other volunteers to fill the constant gap between the inadequate funding and the ever increasing need. My students and I owe an immeasurable debt to the small band of volunteers who have so willingly given of their time, talent, and energy as teacher's aides, computer trainers, job coaches, and empathetic listeners. Paul Marshall, whom you will recognize as the author of *Paul's Place*, was our first computer

coach and largely responsible for demonstrating the benefits of computers in programs for people with disabilities. My students now "surf" the net, send e-mail around the world, do computer job searches, submit resumés on-line, print our classroom newsletter, type assignments, and have a wealth of information at their fingertips due in large part to volunteers like Paul, who helped raised money for equipment, then taught us how to use it.

The labour value of my volunteers is incalculable. I'm afraid it would equal my entire budget and then some. But more to the point, how do you assign monetary value to such important, humane, and much needed work? It would be impossible to suggest that any amount of money is adequate compensation for such contributions.

Now that my family is well grown, and my teaching career long established, I once again have the energy, time, and my husband's support to become a community volunteer. I no longer dress dolls, I work on numerous committees, both local and provincial, which I hope make a difference in the way special needs individuals are seen and supported in their personal and working lives. I am grateful to have a "second chance" to help make a difference.

Finally, no honour can surpass the comment "You must really care about me, you did it for free." Many times over the years, I have heard variations on this theme addressed both to myself and to my volunteers. To know that one's efforts are freely given, with no strings attached, is ennobling beyond measure for both the volunteer and the recipient. §

Volunteers in Recreation

STEVEN SMITH

My name is Steven Smith. I live in a small rural community in southern Ontario, Canada, near the U.S. border. I have cerebral palsy and need to use a battery-operated scooter for long distances. I can walk without help around my home. I enjoy sports and talking to people.

I am a member of a handicapped baseball team. I need a volunteer to help stop the ball when it gets past me on the field. They give it to me and I throw it to my team-mates on base. My baseball volunteer is an important member of the team and in winning the game.

I have other volunteers who take me to the movies, tie my shoes, help me with my coat when needed, and make it possible for me to attend community events. Without volunteers, I would be at home and doing nothing.

I would not know what to do without volunteers. I have a close relationship with all my volunteers and we talk, listen to each other, and understand each other.

I think of my volunteers as friends who can organize a program so I can go out in the evening.

§

Volunteers in School

BELINDA KLIGMAN



Belinda Kligman

Belinda lives in Burlington, Ontario with her parents, her dog Pavel, and her cat Snepsts. She enjoys reading, listening to music and crocheting for her friends.

I have used volunteers in various roles throughout my school career. Most of these people come to me because of my mother's pushing the staff at the Halton Board of Education and my schools to help me achieve normalcy in life in areas where my disabilities hampered my growth. These people were very intimidated by my mother, so when she made a request, they followed through on it ASAP.

Examples of volunteers I have had are a social skills coach, an educational assistant in mathematics, science, music, and art, a teacher who worked with me on a gross motor program during physical education, a special education teacher who came into my grade nine math class to help keep me from being put down by other grade 9 students, and a grade 12 male student who buddied up with me to help me be able to attend a normal grade 9 physical education class and attain my necessary credit.

The people who helped me throughout my life showed me that my abilities were just like those of other people my age. I just needed extra help, understanding, and time in order to succeed. They helped me realize that I was not going to get in trouble if I tried my best at everything I did. Without these volunteers I wouldn't be able to make most decisions on my own and deal with friendship conflicts on my own. I can see now that I was a good part of the problem and that I unfairly accused and blamed these people when put in a spot where I had to admit my wrongdoing.

I also have been a volunteer at Joseph Brant Hospital since I turned 15. I work very hard when I am there because I enjoy the work and the people I work with. It gives me a feeling of accomplishment and pride when I finish a task. It has also helped me learn.

§

AS COMMUNICATION CHANGES

ALDA STEPRANS



Alda Steprans

Alda updates us on Steve and Audrey who share their views of volunteers with us next, and introduces two other contributors to this issue's As Communication Changes.

Steven still likes to be described as a happy, crazy fellow. One of his favourite words, this past while, has been crazy. He admires craziness, craziness in the sense of not the usual, of zaniness, being a bit outlandish. He still enjoys having lots of fun with everyone around him and when he tells me what to write his sense of humour is so wry, I cannot always tell when he is serious. Hence some of the "ha, ha's" in his article. Steven's patience when he tries to express himself is incredible. I often wonder where he draws this patience from, as he tries to communicate what he wants to tell us, again and again and again.

Audrey has had more ups and downs in her life. She recently got a motorized wheelchair, which has really increased her independence.

She has enjoyed driving out into the community and has slowly travelled farther and farther from the hospital where she lives. Unfortunately she tipped over in her wheelchair recently, trying to get into a church. She was badly bruised, especially in her face, and she broke her arm. Despite the fright she took she is back out driving her chair, getting her confidence back. The episode was very frightening for her. I can only admire her attitude in getting back out. It helps her to have friends and staff to support and accompany her, until she feels fully confident again.

Dorothy Brace is a valuable volunteer at Runnymede Chronic Care Hospital and is one of those people who always seems to wear a smile and have something positive to say. She really values all those around her and I've often admired her ability to appreciate just being with other people. The residents at Runnymede look forward to her visits very much! Volunteers are so valuable to those who live in the

hospital. They provide so much, often by doing the little, simple things that make life easier and more satisfactory that no one else seems to have the time to do. Never underestimate the importance of one person's smile on the life of another!

When I asked some of the residents of Runnymede Chronic Care Hospital what they thought of Sherri Maggiacomo, the head of the Volunteer Department there, I heard that she is a nice, patient person, who always takes time to listen. They mention that she goes out of her way to find ways to help them. Personally, I enjoy her energy as she seeks volunteers who could fill some of the voids in the residents' lives. Volunteers are not easy to come by. I recently applied to be a volunteer at Runnymede Hospital, too, and was impressed by the care Sherri takes to protect and assist both volunteers and residents. Being a volunteer may not take more than a few hours every week, but it is a large responsibility, especially because the residents look forward to them coming so much. §

Please Note: New Rates for Communicating Together (starting with the Winter issue, 1999)

	ISAAC Members	*Non-ISAAC members
Canadian	30.00 Cdn	35.00
US	28.00 US	33.00
International	34.00 Cdn	40.00

Rates for consumers, students, seniors

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The Crazy Volunteer / The Crazy Volunteer Lover

STEVEN HANLON

I did a lot of volunteer work before I got Huntington's Disease. I helped in a school with all sorts of things. The kids were of all ages. We did different things. As many of you now know, I love sports and I helped the kids with sports. We ran and played volleyball. I would teach both boys and girls. We also did crafts. It was a lot of fun for me. For three years I also helped children and adults who were disabled to bowl. I loved that - especially

meeting so many nice people. I was working then and helped in my spare time.

My favourite volunteers here at the chronic care hospital where I now live are the ones who get me beer (ha, ha)! Seriously, I especially like the ones who play games with me, like euchre and dominoes. I love playing games! The volunteer who plays euchre with us, Helen, had been sick - I missed her a lot. I am glad she is back now. Audrey, the other resident who writes articles for this magazine, sometimes plays games with me even when there are no volunteers around. The volunteers know that I cheat a lot whenever I play. Cheating makes the game interesting and it is lots of fun. No

one here gets upset by it. They know I do it for the pleasure of making everyone laugh. Lois, who works in the Activities Department, helps me with Wheel of Fortune on the computer. I think a volunteer may help with the computer programming, too.

I think that to be a good volunteer you need to be crazy, like me. In other words, you have to like people, have a good sense of humour and lots of patience and you just have to love people. I have never yet met a volunteer I did not like. They are all great!

My dream volunteer would be someone who would get me a beer and join me in drinking it (Ha)!

§

The Very Best

AUDREY MCGEE

They're the best! Volunteers help me and all the residents of this hospital I live in a lot. I am writing a book and a special volunteer, Minette, comes in to help me with it every Monday. Nicole, the hospital's speech therapist, found her for me. It takes a lot of time and patience for Minette to help me. She understands me!

Volunteers also come in to play euchre with me and some of the other residents every Tuesday evening. The volunteers are very nice to be with — they are special people. Sometimes the volunteers are sick and cannot come in. I miss them very much when that happens. I long to see them.

Even though I can't talk, the volunteers take time to understand me. But, even though there are a lot of volunteers at the hospital, not many come in on the weekends. I am busy during the week, but get very lonely

Saturdays and Sundays. Long weekends are the worst — three whole days of little company.

Barb, the occupational therapist, took me to a nearby church, but it was locked. I am not sure I would have been able to get inside with my wheelchair. The volunteer coordinator at the hospital is trying to find a volunteer who would bring me to church. The Salvation Army comes into the hospital and I attend those services, but I would like to go to a Catholic church. One of the other resident's daughters brought me to a wonderful church at Bloor and Islington — Our Mother of Sorrow. There was an elevator there I could use to get in. We went by Wheeltrans. This wonderful lady also invited me to her home for dinner. I also went there by Wheeltrans. She has a dog named Babe. Unfortunately, her home was not totally wheelchair accessible — so many places are not. It took her, her husband, and her daughter to lift me in my wheelchair up some stairs to get into her house!

Volunteers help many people in the hospital. They take them out into the garden, walk them around and talk to them. They accompany them on trips outside the hospital and help make our social functions and parties even more fun. They may not feel that they are doing much, but they make a tremendous difference. They are all so different - some are old and some are young, some male, some female. I look forward to seeing all of them and especially to having the chance to talk to them. Their company is what I appreciate the most.

Volunteers also play a role in safety. One day a resident who is not supposed to be outside alone, did come out to the garden. There are cars that drive through the lot and this resident cannot safely manage crossing the lot without help. I told one of the volunteers and she took her back to where she would not get hurt.

Albert, the gentleman who helps me with my painting, is also a volunteer. You know from my previous

articles that I learned to paint at the hospital. I have had to learn to use my left hand to control the brush and it has been hard, but it has really made me feel much better about myself. I feel as though I am giving something back. My paintings have traveled far. One of my paintings has gone to Australia for an exhibit. The head of the Activities Department, Stella, arranged that.

Another painting is in Malta - I gave it to a friend of mine. One of the nurses brought one of my paintings to her mother in England. That makes me feel special.

Before my stroke, I used to volunteer for the Cancer Society. I received a special pin and diploma for 25 years of volunteering with them. I especially helped on Daffodil Day when I would

knock on doors and canvas for donations. I have also canvassed for the Heart and Stroke Foundation and The Salvation Army.

If I had a dream volunteer it would be someone who would take me to all the malls and shop with me — window shopping or buying something I like!

§

The Currency of Caring

DOROTHY M. BRACE



Dorothy M. Brace

Most sources define volunteer as to offer one's services... time... to give of one's service without compensation.... I beg to differ, the compensation received as a volunteer is beyond any monetary value. I have volunteered at a chronic care hospital for several years, and feel far richer for the experience. As I neared my retirement years I became more aware of my own mortality and the needs of those around me, and decided to embark on a journey into the world of those less fortunate than myself.

At first I felt inadequate if a resident was only able to speak their native tongue and I did not know it, but hand gestures and a smile are universally understood in any language. For those unable to communicate verbally, it proved to be just as easy. To admire a blouse or shirt, compliment a new hairdo, notice new family pictures, all bring a smile of understanding. Just because a resident cannot speak doesn't mean they cannot understand — as I have discovered, there are some sharp minds at work there!

Residents who can communicate verbally love to share a volunteer's life as you share in theirs. Some like to discuss world affairs — books — gardening — grandchildren. You find yourself putting on different hats as you visit each resident. I am known as the cat lady as I usually wear funny cat T-shirts or jewelry and always have a new story to tell of my three furkids! Residents love to discuss their own lives and hear about yours, little things that may seem insignificant to outsiders are an event to shut-ins.

I have also learned that being a volunteer releases any inhibitions that you may have. I have dressed up for Halloween at age 64 for the first time in my life! I have held conversations with imaginary people and

agreed to do errands that will never happen, all to calm a wandering-worrying mind. It is very gratifying when you are able to calm a resident into eating supper when you tell her you will take care of her worries.

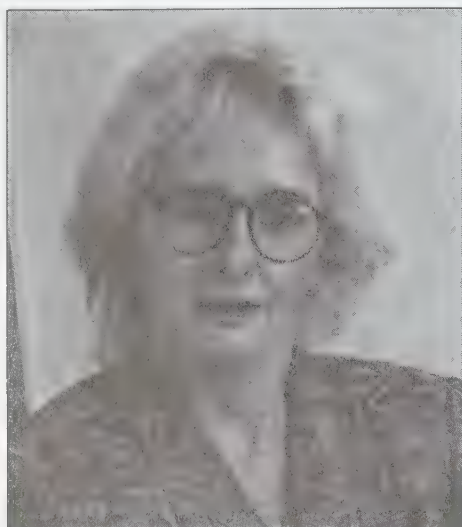
Then there are the smiles — the beam of happiness when I put Bessie's glasses on. Being short-sighted myself, I know how it feels to be without them. The giggle as I hold Carrie's hand while feeding her with the other and make a funny remark about the food on her tray. The proud smile when I admire the picture of Carlotta's latest grandchild — no interpreter is needed for this.

Volunteering at a chronic care hospital does not have to be a sad experience. Yes, sometimes there are tears — but there are plenty of smiles and laughter. Do not enter into this experience with pity, the residents do not feel sorry for themselves. They have a palpable joy in life — more so than many healthy people I know — and only ask for a helping hand to do things that we take for granted. If you have some time to give to those less mobile than yourself, go into your community and find a facility that needs help. Your life will be richer for the experience and the compensation will be bankable in any currency.

§

Three Cheers for Volunteers

SHERRI MAGGIACOMO



Sherri Maggiacomo

As Christmas approaches and the elves are hard at work, it brings to mind the experience I had last Christmas. As a tradition every year the volunteers at Runnymede Chronic Care Hospital stuff stockings for our residents. These individual stockings are delivered by Santa in the wee hours of the night and placed at the foot of each resident's bed for Christmas morning. I have participated in this tradition for many years and always appreciate how it truly brightens our residents' Christmas.

Last year after I returned to work after the Christmas holidays, one of our residents, eighty-six year old Peter, called me to his bedside. I

asked Peter if he had a nice Christmas. He responded, "The best in years." Peter explained that Santa had visited Christmas eve and had left a stocking of goodies at the foot of his bed. Peter let out a boisterous laugh and said, *"I must have been a good guy this year! I have not seen Santa for years."* He proceeded to describe to me item by item the contents of his stocking. I listened intently, only to realize Peter had not missed an item. The joy he felt reminded me why what we do as volunteers is so very important.

In my role as Volunteer Coordinator, I have the unique opportunity to witness first hand the difference our volunteers make in the lives of our residents.

Volunteers assume many roles within our facility. For instance, in our Friendly Visitor Program, I introduce new volunteers to our residents and watch as their relationship blossoms into a lasting friendship for both the resident and volunteer. In the Mealtime Assistance Program, volunteers encourage residents to consume their lunch or dinner, and as I listen, I realize it is no longer just a meal, but is now a social event. Our Activity Therapy Department coordinates monthly out-trips to locations in the community, with the help of our volunteers. I watch the anticipation of the residents preparing to embark on their journey and see the excitement when I inform them their favourite volunteer will be accompanying them. Like so many other daily routines within our facility, out-trips would not be possible without the support of many dedicated volunteers.

We are fortunate to have a team of dedicated, loyal volunteers who are always willing to go that extra mile, not only within our facility but extending into our community. Volunteers in the community contribute by knitting afghans, lap robes, slippers and various other items. These beautifully handcrafted items are collected year round and at Christmas are individually wrapped. Christmas Eve, Santa delivers these special packages to each and every one of our residents.

Regardless of what role they are assigned or what duty is performed by our volunteers, all contribute to enhancing the quality of life of our residents.

It takes a very special individual to walk through the doors of a chronic care facility. Working with individuals with cognitive and communication deficits presents many challenges. I have continuously observed our volunteers tackle these challenges and turn them into successes.

Once you have passed through the doors of Runnymede Chronic Care Hospital, you will find a volunteer position which provides many rewards. It may be a smile, touch of your hand, new friendship or just genuine appreciation from a resident because you have taken time out of your busy schedule to brighten their day. The rewards are endless.

The year 2000 has been designated the Year of the Volunteer — what a wonderful way to start the new millennium.

§

CONTEXTS

Volunteering: doing, acting, being able to do of one's own free will.

GEB VERBURG



Geb Verburg
(*Volunteer in Spirit*)

This is one of the harder articles I have written in a while. Volunteering and community action are both laudable and satisfying activities which are becoming almost a necessity for survival in these times of cut-backs and restructuring. Most of the articles in this issue focus on volunteering as a practical, positive, and rewarding activity engaged in voluntarily.

I wanted to include some of the wider social and economic issues. This brought me to James Laxer's *The [undeclared] war: Class conflict in the age of Cyber Capitalism* (1998) and Jeremy Rifkin's *The End of Work: The decline of the global labor force and the dawn of the post-market era.* (1995). These books set the scene for this article. The two authors, one Canadian and one American, have made some

remarkable points about the path upon which they see our society traveling. It is a path that according to Rifkin leads to a near workerless society and the renewal and rise of the "Third Sector", that of volunteering and community action. Laxer covers similar ground but sees a scenario in which wage earners of all stripes and persuasion will unite behind the banner of the dominated class, i.e. the wage and salary earners or workers, against the dominating class i.e. capital, in a "social explosion" (p 248).

I am trying to understand how volunteering fits into the social and economic future that is being mapped out by the current world powers. And the more I read, the less I like what I read, and the less I like what I see around us. I have long since stopped reading newspapers because they are so biased in favour of the dominant capitalist worldview and therefore are so irrelevant to the well-being of everyone else and their environment. I have gradually changed my lifestyle, with a little help from a friend, to embody two guiding principles: (1) the minimization of consumption, (I buy as little as I can); and (2) the maximization of value for money (I refuse to buy what is sold at regular price, and I try to refuse to buy things that have just novelty value).

When I was a student (activist), in the late sixties and early seventies, we thought that we were being taken advantage of by big business and multinational corporations. In the 30 years since, the multinationals have not rested on their laurels; they have globalized. The gap between the rich and the poor has become a giant and still growing chasm. What we used

to call a lack of consciousness has evolved into a strange state of disempowerment, the likes of which has not been seen since the times of the serfs or slaves.

It looks like the only people that are doing things out of their own free will are volunteers. Everyone else is in fear of being downsized, or of losing their jobs while already doing the work of two people. At the other end of the spectrum people are trying to attain double digit profit increases so that the faceless shareholders will once again be satisfied. Could it be that we could take some lessons from volunteers? Can we learn again to do and act, and offer service out of our own free will?

Volunteering

The root of volunteering is *voluntas* or will. The Dutch word for volunteer is *vrijwilliger*, which contains the words free and will. Volunteers are thus people who do things of their own free will. Voluntary, according to the concise Oxford dictionary is: done, acting or able to act of one's own free will. What does volunteering, this simple process of doing things out of one's own free will, usually for free as well, have to do with the course of economic and social forces?

First cut

In a nutshell it goes like this. Corporations are restructuring and automating (and so are health care, government, universities, the military, and the service industries) and as a consequence more and more people are declared surplus and become unemployed. Rifkin argues convincingly that in this Third Industrial Revolution no significant

numbers of new jobs are created, and those laid-off gladly accept jobs at a fraction of their previous wage. Both he and Laxer observe that wealth redistribution has ceased to occur with the silencing of the unions and the demise of the Soviet Union. Big business and big capital believe there are no incentives to share their wealth.

We will therefore be faced with a very large number of people who are unemployed or unemployable. We might call them "Rifkin volunteers" because, although these people have plenty of free time on their hands, they are certainly not volunteers in the current sense of that word. They are a veritable army of involuntary volunteers. Once upon a time governments could afford to pay unemployment insurance or employment insurance (EI) as our government so euphemistically calls it.

As more and more people are laid-off or restructured out of the workforce into penurious part-time work, all our governments' income bases will proportionally be reduced. It is, after all, the wage and salary earners who now provide the bulk of government tax revenue. For every wage earner who loses his or her job, the government loses tax income and incurs expenditures in EI. There is very little chance that government will actually start taxing big capital and/or big business. And even if it did, globalization has safeguarded every large corporation from being taxed in any particular country. And so, government too will have to restructure, retrench and redefine its priorities. One of the first groups to suffer will no doubt be the unemployed, the unemployable, and probably also the disabled.

The Chasm: The increasing wealth of the few "super rich" and the increasing poverty of larger and larger masses of people. Wealth is somewhat like a pie. For every

person who takes a larger piece, others will have to settle for smaller pieces. As the greediness of some increases, the pieces for more and more others become smaller and smaller. Laxer, Rifkin and many others have noted the growth of the gap between a relatively few rich and the increasing multitudes of people who are poor and/or getting poor(er). That includes those who lost their jobs but also the "lucky" ones who still have their jobs but have not seen a salary increase in years.

Rifkin sees the growth of this chasm between rich and poor as a consequence of the greater efficiency and profitability of production due to automation and restructuring. The same processes result in layoffs and the gradual emergence of a workerless society. Rifkin shows statistics which uphold a move towards such a society. Laxer also believes that we have not nearly seen the end of corporate, government, educational, and health care restructuring. I am terribly afraid that he is right and why shouldn't he be? Companies, governments, hospitals have never had such an easy way of increasing their profits or cutting their costs. All they have to do is fire a portion of their work force and encourage the remaining staff to (volunteer to) do the work of the ones fired.

The sad thing is of course that we, the workers, actually comply. Happy to just hang on to our jobs, we work harder, worry more, probably earn less. Our jobs are so important that we keep them no matter what. They are necessary for our food, our mortgages, our children's education. We must work, we have no choice, we cannot afford to act of our own free will. That's what has been bothering me about the current state of capitalist society. Capitalism, with the fall of Russia, has entered a stage of arrogance and open unconcern for the workers that

cries out for a response. The current capital economy is such that it favours the people who have obscene amounts of money and who make even more scandalous sums. I am not just thinking of the world of the Gates. Your own bank president probably falls into this category as do other members of increasing numbers of "gated or walled" communities in our neighbourhoods.

Whether Rifkin's view of the future is right or wrong his observation that the commodity value of people's labour is vanishing (p. 216) is bound to be true in a world in which sectors of the population (youth, blacks, underdeveloped countries) face from 20 to 50 percent unemployment. In one respect the dissociation of our labour from our sustenance is beautiful because it has always been degrading to have to sell one's labour, or to spend our lives in servitude. On the other hand the loss of the commodity value represents more than a sociological change. It also implies a profound personality change. Most of us who work and have worked for all our lives have built our identities around our work. To lose our jobs means to lose our identity. That is a blow which can be very difficult to accept.

For people who lose their jobs a social change or social learning processes must happen. They have to accept the fact of their lost work identity and learn to rebuild a new identity not as a "worker" but as a volunteer and still be equally proud of it. It may be up to professional volunteers (the Nola Millins and Paul Marshalls) to help teach these skills by sharing their pride and showing the way. If this societal change does not occur we may be in for something really catastrophic. Nathan Gardels (in Rifkin p. 215) characterizes the unemployed as follows: "we don't need what they have and they can't buy what we sell". And he "foresees

an increasingly lawless and foreboding future — a world populated by ‘patches of order and swaths of pandemonium.’” Is that just the conservative scaremongering of Rifkin? After all, in his book (pp 208 - 217), he zeroes in on inner city crime, school violence, youth gangs, and makes this appear to be a global rather than just an American problem. Or are we really heading towards a time when social conflict, pandemonium, or some form of non-peaceful redistribution of wealth is going to happen?

Options?

The Third Industrial Revolution will not stop because one of its consequences is that it puts people out of work, nor because its profits are inequitably distributed. On the contrary, new (automated) production methods will continue to be developed and new, cheaper, more abundant products will keep flooding the market. And as long as there are enough workers left who earn enough to buy those products, then the capitalist economy will continue to churn out products for the many, generating

profits for the few, minding very little how much damage is done to the people who are unemployed or to the environment in the process. The wonder of the present day is that no-one knows whether the Information Age with its Third Industrial Revolution will actually deliver upon some of its beauteous promises of wealth and harmony. Will it produce the myriad jobs (cottage industries, home jobs, millions of one-person home-offices doing millions of unique and presumably sellable or swappable services, arts, crafts, cultural, political, social, community activities) that are needed somewhere? Will we see the creation of the Third Sector, a voluntary army of people working for free for the betterment of their environment, neighbourhoods, personal experiences, their (our) cultural, social, intellectual well being? Or will it not deliver and are we all being pacified with false promises until the next stronger whip or soporific will be administered that will keep us working or hoping a little longer for that bright and super highway future? Is it all super highway robbery?

Are we walking with open eyes into a future where we will not even be able to afford volunteers, because, there simply is no money, other than what the “super rich” are willing to dole out for their personal pleasure, whim, or charity? Can we avoid or forestall Laxer’s revolution or a wealth and power redistribution by violent means?

I am an eternal optimist, perhaps a skeptical one, but I like to hope that a peaceful transition is possible. I cannot imagine living in a time that is more charged with opportunity and danger. I have no idea how it is going to happen. But I am convinced that within the next 5 to 15 years, the social and economic structure of our society must and will change. I only pray that it will be a peaceful change and that as many of us as possible will have a say in that metamorphosis.

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AAC: AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

*The Official Journal of the
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Involving Yourself in Your Community

PAUL MARSHALL



Paul Marshall

The theme that we are talking about in this issue of **Communicating Together** is very close to my heart. I believe very deeply that volunteering, being involved in each of our communities, is the backbone of what keeps many things going. There is no doubt that without people working behind the scenes, things just would not get done, especially in the field of AAC. With all of the cutbacks that we are seeing today, it is vital that the mindsets of community partnerships and voluntary involvement are a very living part of the world.

Generally, we think of volunteering as something that we do if we can fit it in after our work responsibilities or after we retire. There are many benefits that might not come to mind when we think of the personal and community gains when volunteer and community partnerships happen. Some of the benefits that come to my mind are: (a) Jobs that just do not get

done by the work force, are being done by the volunteer work force. (b) We have a better society when people work together to reach community goals. (c) Volunteering creates an active mind, which in turn, benefits greatly our social standards and health care.

There might be an unspoken creed in many societies, especially in the western culture, that creates a mindset that produces the following: money, jobs and ownership of land and material things is where life is. When I was thinking about writing this article, I was reminded of some systems in our history that were run very differently. These were the systems where there was not so much independent living and independent duty to survive. At this point in my life I can put in huge amounts of time doing work on a volunteer basis. As I also said in one of my past columns, I receive a monthly disability pay cheque that allows me the opportunities to give myself to my volunteer commitments.

Why does Paul think the way that he does, you might be wondering? Really, there are two reasons. I am not a person who could sit around. Sure, I wish I had a bit more time for reading and going for more bike rides, but I just do not at this point in life. I have spent many years on the receiving end of things and now I have a few skills where I can help by giving back to my community.

The big question facing us in the AAC community is how do we nurture partnerships and voluntary involvement today? I think what keeps me going is: I can not change my yesterdays; I can however look to my tomorrows as a new

page to write on. I hope my and our new page will be full of links, linking people to people. This is how we develop community partnerships and produce voluntary involvement to go into our tomorrows, writing a new page of history.

This time as part of *Paul's Place*, I have asked two of my colleagues, Anne Abbott and Bernard O'Keefe to write about a new consumer advocacy group I am particularly interested in — *The Greater Toronto Area AAC Advocacy Group* (GTA AAC AG). As vice president pro tem for the group, I wrote the following creed:

A CONSUMER ADVOCACY CREED

We will lift up our silent voices as one voice to be listened to. We will make known our plight so that others can benefit. Gone are the silent issues. We will advocate for individuals who have no voice.

Many of you will remember Anne Abbott. She wrote the lead consumer article for the Spring issue of **Communicating Together** the theme of which was sexuality. Bernard O'Keefe is also well known in the AAC field. He is on the faculty of the Department of Speech-Language Pathology, University of Toronto. He has been a major support in helping us get this new venture going. Listen to what they have to say. I have given the contact information at the end of their article. §

A Consumers' Advocacy Group: The GTA AAC AG

ANNE ABBOTT &
BERNARD O'KEEFE



Anne Abbott

Government policies rarely require that the people who publicly deal with some 200,000 Canadian augmentative and alternative communicators have the opportunity to communicate with them or that they have the knowledge of how to do so. Because of this, people who are non-speaking are essentially excluded from receiving many of the community services due to them and from those activities that provide for a rewarding quality of life. As a result, a group of consumers has joined together to form The Greater Toronto Area Augmentative and Alternative Communication Advocacy Group (GTA AAC AG). The GTA AAC AG hopes to provide that missing voice for those who have been so long unheard. It is our hope that other AAC communicators who would like to establish consumer-directed advocacy groups will do so. The executive councillors of the GTA AAC AG would be most pleased to share their experiences with them.

Purpose of the GTA AAC AG

The purpose of the group is to advocate on the part of individuals who have little or no functional speech, with local, provincial and federal governments. The group also works toward educating the public-at-large on the needs and benefits of reducing barriers and increasing opportunities to people who have little or no functional speech.

The Need for Advocacy Groups

There are numerous social, community and educational barriers that people who are non-speaking and who rely on AAC encounter on a regular basis. And yet, until now AAC users have had no consumer-driven group of their own that aggressively seeks to influence public policy or educate the general public regarding matters related to persons who are essentially non-speaking. While there are important, larger groups that advocate for persons with disability, the GTA AAC AG will help to ensure that the specific barriers faced by persons who are unable to speak are recognized and removed. People with disabilities often feel totally without power or influence. People who are non-speaking feel a particular sense of lack of empowerment. It is more difficult for them to speak up for themselves and to have a say in matters concerning their own lives. They express endless frustration with the reality that they cannot reach their highest level of independence because they simply are not allowed to do so. Despite a strong and natural desire to be a full player in community life, they are rarely allowed the opportunity. This is not because people are uncaring or unwilling to accommodate such longings. More often it is simply that they don't recognize the capabilities and aspira-

tions of non-speakers. As a result, many potentially contributing citizens and taxpayers instead live out their lives on the sidelines, experiencing little, learning to be helpless, and becoming a burden on their fellow citizens. History tells us that when an individual with a disability has the access and opportunities to make life better, he or she will do so. And they will go on to help others with similar disabilities by serving as role models and resources.

Identified Issues

The Greater Toronto Area Augmentative and Alternative Communication Advocacy Group has identified a number of issues of particular importance.

- *Housing*: more opportunities for independent living; the right to clean and appropriately appointed living environments.
- *Attendant care*: more say for the person with little or no speech to direct his or her own care; work toward better training of attendants; help to encourage an atmosphere where attendants are committed to their work and hold respect toward persons with little or no speech.
- *Jobs*: Reduce problems associated with accessing government employment services; remove problems with the Equal Employment Act; increase the availability of supported and sheltered employment.
- *Transportation*: achieve transportation on demand; improve dependability of services; provide transportation in suburban and rural areas; educate drivers who know little or nothing about persons with little or no speech.

- ° *Physician education*: Reduce the tendency for doctors to ignore persons with little or no speech in favor of their attendants or facilitators during examination and treatment; advocate for providing information about AAC during medical training.
- ° *Police education*: Teach police to deal with persons with little or no speech whether in formal situations such as court or when they are encountered in the streets — for example, to recognize differences between persons with little or no speech and persons who are intoxicated.

- ° *Friendship*: Help to reduce the tendency for persons who are non-speaking to have only “paid friends” because of lack of opportunity to meet and relate to others with similar communities of interest.
- ° *Leisure*: Work toward leisure activity choices for persons who are non-speaking rather than having activities imposed on them; increase the number and breadth of opportunities available.

What Can You Do to Help?

First, encourage others to take a moment to learn how a person who uses AAC communicates, to be a bit patient, and to enjoy a unique and creative conversational experience. Second, support the efforts of groups like GTA AAC AG to ensure that the barriers to communication that AAC users encounter both in public institutions and in their day-to-day activities are reduced today and totally removed tomorrow.

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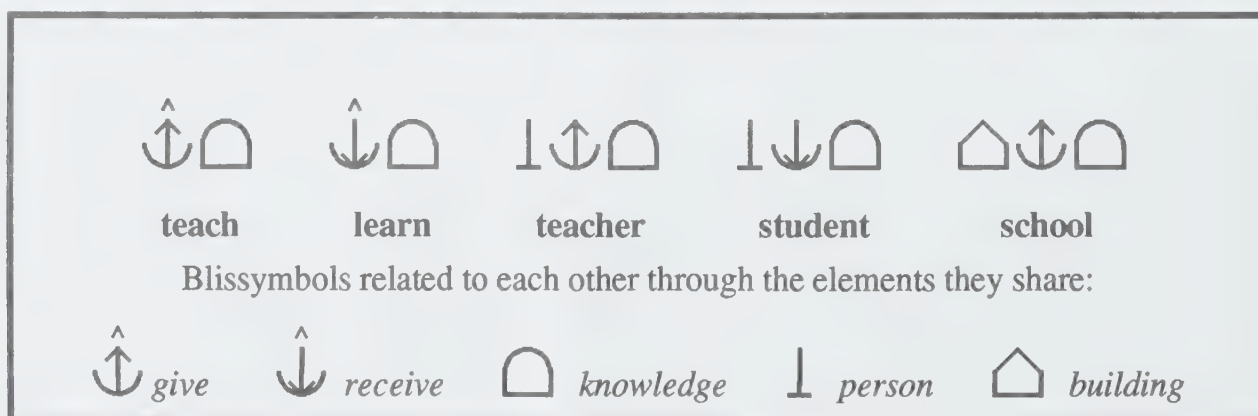
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Climbing the Literacy Ladder

SHIRLEY McNAUGHTON

In *Paul's Place*, in the Summer 1998 issue of **Communicating Together** (Volume 15, Number 2), I described BlissInternet as our agent of change and promised to say more in a later issue regarding BlissInternet's capability to support Bliss users and Bliss alumni as they progress toward literacy. This issue's theme — *Community Partnerships and Volunteer Involvement* — provides the perfect context. My focus in this article is literacy acquisition for adults who use AAC. Many of the points, however, have application as well to literacy development in children who use AAC. Hopefully what I have to say will have relevance to those wishing to help persons of any age who communicate with Bliss, pictures or print and who wish to improve their literacy skills.

The literacy program I am presenting has the acronym WRIB — *Writing and Reading with the Internet and Bliss* (McNaughton, 1998). "WRIB" provides an easy reminder that it performs a similar critical function in literacy acquisition as the ribs perform for the organs of the body. The rib case provides a structure to support and shield internal organs vital to our survival. WRIB provides a structure to maintain and support the further development of the individual's literacy abilities. And I use another analogy — considering literacy acquisition as climbing a ladder that depends for its stability upon a strong supportive platform.

The literacy ladder has three rungs — pictures, Blissymbolics, print — each of which offers access to rich learning experiences. Only the top

rung, however, opens the full world of literacy to the learner. It is a level to be highly valued, especially for AAC users. For them print literacy not only opens the wide world available to all literate persons, but it also affords choices within many types of communication — face-to-face, with spelling/word boards and voice output communication aids (VOCA's); written, with many computer software options; telephone, with VOCA's; and computer-mediated telecommunications, using e-mail and the internet.

The supportive platform upon which the literacy ladder depends rests on four legs — (1) the learner's abilities and motivation, (2) knowledge of the factors involved in learning to read, (3) a supportive instructional environment and (4) a committed instructor. I know of many situations in which one or two of the platform legs are in place, but one or more are inadequate — and the ladder topples! In those instances where all four legs are strong, the upward climbing of the ladder is a rich and satisfying experience for both the learner and the instructor.

Literacy Ladder

First, let's look at the literacy ladder. At the *first* rung, AAC users learn to use pictures or line drawings to communicate. At this level they can gain knowledge as they sequence pictures or line drawings to tell a story or to convey a message and as they interpret a series of pictures and drawings to gain information. The learner can derive lots of enjoyment and self esteem through participating in these "literacy" activities. As Detheridge and Detheridge (1998) describe this level of literacy, intellectual development is freed "from the constraints of writing and spelling, allowing language development to be

successfully explored at an early stage" (p. 30). They report that many teachers claim, "by providing the means for structuring ideas and communicating knowledge it is possible that some learners will exceed expectations and will acquire higher levels of literacy than were initially anticipated" (p. 30). Their book, *Literacy Through Symbols*, contains many helpful examples of what can be accomplished through individuals participating in the domain of written symbols. As AAC users read and write with pictures, they can learn that graphic symbols convey meaning, that graphic symbols are sequenced from left to right and they can become aware of the arbitrariness of form-meaning connections. They can also develop a sight vocabulary through recognizing the words paired with their symbols. For a better understanding of the similarities in how pictures and sight words are processed, see the description of Type One (holistic processing) and Type Two (analytic processing) symbols in McNaughton (1993) and McNaughton and Lindsay (1995).

But there is more to be gained at the *second* rung of the ladder, for this is where the language capabilities of Blissymbolics can greatly enrich the symbol literacy experience. Here, is where Type Two symbols (McNaughton, 1993; McNaughton & Lindsay, 1995) become available to the learner. As individuals "read" and "write" with the more arbitrary and rule-based Blissymbolics, the duality of this language system can add to the learning experiences acquired on the first rung of the literacy ladder. The language of Bliss provides two levels of structure in which discrete units can be combined.

At the symbol (word) level, the meaning elements can be analyzed, or

segmented and re-combined to form new symbols. The meaning of each symbol can be discovered through knowledge of its components. Families of symbols can be discovered — related to each other through the elements they share. [See examples of related symbols following References on page 20.] As individuals gain fluency in analyzing the Blissymbol elements, they develop an important skill for the *print* rung of the ladder that is waiting just above the Blissymbol rung.

At the sentence level, with the grammatical components Blissymbolics provides, learners gain more knowledge to support the reading of print. As individuals write with Blissymbols, they learn rules to enable the sequenced symbols to form statements or questions or commands, and to denote plurals, possessives, pronouns and verb tenses and negation. The combinatorial capability of Blissymbolics is so powerful that there is no limit to the number of symbols and sentences that can be produced. As learners read and write with Blissymbols, they gain experience with symbol elements and with syntax and they acquire the underpinning for the rules of their native language. They learn how to analyze symbols and sentences and apply this knowledge to creating new symbols and constructing original sentences. These experiences provide critical preparation for progressing to literacy fluency. For the speaking child this language foundation comes from their many years of talking and listening. For the AAC user, this language foundation must be acquired through the mastery and control of their expressive AAC communication being added to and refining their listening. This can be achieved through experiences with the dual structure of Blissymbolics. *Duality* provides the valuable additional learning opportunities at the second rung of the ladder. It's Bliss!

On the *third* rung of the ladder, AAC users read and write with words (print). Some of the words will be instantly recognized from seeing them along with their symbols or from books or from signs in the environment. These “sight” words can be “read” without having to analyze them or think about the sounds their letters represent. This kind of reading is similar to the reading that is done with pictures, when the processing is holistic and no analysis is required. The reading of sight words is possible, however, for only a limited number of words. Soon the learner will encounter many words that have not been seen before and for which analyzing and decoding skills will be needed. It is for this “reading” that the experience with Blissymbols at the second rung of the ladder can be helpful. Both Blissymbols and words require analysis and decoding. The analyzing to be done with words, however, differs from the analysis required of Blissymbols. Research has shown print analysis to be more difficult than Blissymbol analysis for early readers (McNaughton, 1998, pp. 131, 189). Because the analysis of a Blissymbol into its meaning parts is more easily learned at an earlier developmental level than the analysis of words into their sound parts, the second rung of the ladder offers a time for enjoying and learning about written language before climbing up to the more difficult demands of reading print.

It is interesting to note that for both Blissymbols and words, the meaning or sound associations required of their elements are not always consistent — an important lesson to be learned! For example, in Blissymbols, the small circle sometimes means “mouth”, but it is also used in the handle of the pictographic “scissors” and as a link in the chain denoting “combine”. In print, the sound of the letter “c” is different in “cat”, “cent”, “child”. One of the exciting break-

throughs in reading is in discovering what the associations are from the context of the full symbol (analyzing all its parts) or from the context provided by the full sentence (examining all its symbols or words). It is worth noting that knowledge derived from examining all the sentence elements can be gained at all levels of the literacy ladder — through reading and writing with *pictures*, *Bliss* or *print*. Only Blissymbols, however, provide experience analyzing arbitrary symbol components prior to analyzing arbitrary printed word components.

Literacy Platform

Now that we have seen what is offered by each rung of the literacy ladder, we need to examine what is needed to support the platform on which the ladder rests. For adults who use AAC, the first leg of the platform, the learner's abilities and motivation, may not be immediately obvious. Visual, auditory and language abilities must be assessed to ensure that the learner can function within a graphic language environment. With regard to motivation, there are many reasons for it to be, or appear to be lacking — repeated failure in the past, lack of energy, lack of knowledge as to the benefits of literacy, the mistaken belief that writing and reading are not possible for persons who cannot speak (reinforced by a similar belief on the part of teachers and caregivers during the AAC user's formative years). This leg of the supportive foundation is the first to investigate. In order to know what to look for, we must consider the second leg of the supportive platform — the factors involved in learning to read.

The mainstream reading acquisition research has identified many factors contributing to success in learning to read (Stanovich, 1986, 1991; Share, 1995). The factor that is primary and needs to be considered first is that of *phonological recoding*,

defined by Ehri (1991) as “translating letters into sounds by application of letter-sound rules and then recognizing the identities of words from their pronunciations” (p. 107). A caution expressed by Adams (1990), is important to remember in considering phonological processing:

It is not working knowledge of phonemes that is so important but *conscious, analytic* knowledge. It is neither the ability to hear the difference between two phonemes nor the ability to distinctly produce them that is significant. What is important is the awareness that they exist as abstractable and manipulable components of the language. Developmentally, this awareness seems to depend upon the child's inclination or encouragement to lend conscious *attention* to the sounds (as distinct from the meanings) of words [*italics added*].

(Adams, 1990, p. 65)

Important as it is, it must be remembered that phonological recoding is not the sole factor! To phonological processing must be added visual, language, memory and environmental factors. Above all, the instructor must be aware that literacy must be considered as but one component within the language learning process, developing gradually from infancy onward. AAC users' abilities and their past language learning environments are all of interest in determining their instructional needs. Many ways have been developed to assess the individual's abilities. Whether this be done formally or informally, the instructor has to be aware of the learner's strengths and weaknesses in all of the areas affecting literacy acquisition. Perhaps another *Symbol Talk* can be devoted to an

assessment protocol that has proven helpful to this writer. For now, I will assume that the first two legs of the Literacy Platform are in place — that the learner has the skills and motivation for literacy learning and that knowledge concerning reading acquisition can be accessed by the instructor. The references on page 20 offer readings for those who wish to know more.

It is the last two legs of the literacy platform that I wish to emphasize here — the *supportive instructional environment of BlissInternet* and the *volunteers* who can contribute so much as instructors. BlissInternet provides a medium for the transmission of both Blissymbol and print messages between individuals wherever they have access to a computer and telecommunications. The BlissInternet software is readily available from the two addresses listed on page 20. It affords the experience to acquire the conscious and analytic knowledge of print, identified as critical by Adams (1990). It provides a means for interacting with a resource instructor whenever needed. As an example, a Bliss user in southern Ontario is exchanging messages, stories and “homework” assignments with a Bliss user in northern Ontario. Each partner is learning from the other as they take turns and exchange roles as tutor and learner. A resource instructor makes suggestions as the interaction proceeds. Stories, containing a “friendly” blend of known and unknown words, are being written and shared. They relate to topics of mutual interest. Questions are being asked in Bliss for responses in English and vice versa. Activities are being created and engaged in to give practice in consciously analysing the elements in both Blissymbols and words. Fluency in decoding and spelling tricky words and in processing difficult phonologi-

cal units is the goal. The learning is fun and satisfying. Direct links are being made between the skills already acquired at the second (Bliss) rung of the ladder and those to be learned at the third (print) rung.

And now, the reason for this article fitting so well in this issue of **Communicating Together** with its theme of volunteering and community involvement! Most important of all to the success of WRIB is the fourth “leg” of the literacy platform — the committed instructor who ensures that *attention is directed* to the sounds of words and that the other factors related to print acquisition are considered. Without the assistance and interest of this individual, the entire ladder falls. Here is where volunteering is needed. This role can be filled by a friend or a family member or a caregiver who can donate his or her time to helping an AAC user on a regular basis. It can be filled by a teacher who “volunteers” additional time beyond classroom teaching to help the AAC user who needs extra attention. It can be filled by a more advanced student who wishes to gain experience in teaching. Whatever the reason for the involvement, the volunteer can make *all* the difference! For time is what is needed. Time for the volunteer and the AAC user to climb the literacy ladder together, with the help of other Bliss users or Bliss alumni and with assistance as needed from a resource teacher — a role I thoroughly enjoy! The climb is a satisfying one. Each rung of the ladder brings its own unique pleasure and accomplishment.

I would always welcome hearing from volunteers who would like to know more about or who would like to become involved in WRIB. Do send me an e-mail message if you're interested! I promise a quick response! My e-mail address is: smcn@freespace.net §

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Volunteers with the Wilfred Laurier Music
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